

Information for family and friends

A spinal cord injury is a major and challenging life event. If you know and care about someone who has sustained a spinal cord injury, their injury will also have an impact on you. This fact sheet may be useful for you to consider how you can be involved and where to go for support.

Knowing and caring about someone who has sustained a traumatic injury such as a spinal cord injury can be difficult. Whether the person is your friend, neighbour, partner, child or parent there are considerable and varied emotional responses.

You may also have many questions you need answered or fears and uncertainty about what your future with that person will hold. These may include:

- Will they be okay?
- Will they be the same?
- What do I say?
- What if I say the wrong thing?
- What do I tell the children?
- How will we pay the mortgage?
- Can we still have a family?

Some people have found it helpful to have someone they can talk to about their fears, concerns and worries without judgement. You may be able to find this in a family member, close friend, psychologist, counsellor or spiritual leader. You may find yourself feeling like you are not coping, or feeling very sad and tearful; if this happens you may find it helpful to see a psychologist.

Some people find it helpful to talk to families who are further down the track after a spinal cord injury. The social worker on the ward may be able to link you with individuals or families who can talk about their experience after hospital and any strategies they found useful in helping them through challenging times.

Not only is it important to have someone to talk to, it is important to schedule in some time for you (and

only you). If you have difficulty with work and other responsibilities (such as parenting), perhaps talk to the social worker about getting support services that will allow you to take a break.

Looking after your own health and wellbeing is vital. Eat well, take the time to relax and spend some time for yourself doing things that you enjoy. Have you had any offers of support that may help you achieve this? If possible, pre-arrange some regular support that you feel comfortable with. This could include a friend helping with the groceries, or pre-cooking some meals for you, or someone you trust taking the kids to and from school.

While the person you care about is in hospital, they will be focusing on their own health needs, getting stronger and getting ready to come home. While this is happening for them, it is okay that life outside of hospital continues to move forward, that you take the time to enjoy activities and to celebrate achievements, birthdays and other special occasions.





It may be possible for you to include your family member or friend, if they are well enough to leave hospital for the occasion. Speak to the staff on the ward about whether this is possible.

It is not uncommon for some family members or friends to feel concerned

that they may say the wrong thing and offend their loved one. This may be the first time you have known a family member or friend with a disability. It is okay to feel worried about this. Remember, this is a new and learning experience for both you and the person you care about.

If you are still worried, try to find out as much information about spinal cord injury as possible. There is information about spinal cord injury available in this series of fact sheets and online. If you don't have access to the internet, contact a health worker, social worker or ParaQuad NSW to help you find some useful information.

Children

Children of a parent with a spinal cord injury are also affected by this life event. It is important to give children information about what has happened to their parent using language they are able to understand and information that is appropriate to their age. If you need help or support to talk to your children about spinal cord injury, you may find it helpful to have a member of the treating team present.

If you notice any unusual changes in your children's behaviour, you should discuss this with a health professional. Speaking to the school teacher, school counsellor or another involved adult (such as their sports coach) can be helpful so your child can be supported. You know your child and family better than any health professional and understand what is normal for your family.

References and Further Resources

Contact the social worker on the ward to discuss how you are coping, or to ask for additional support.

Discuss your needs and circumstances with your GP who may be able to recommend a psychologist in your local area; currently Medicare is supporting people to

access a number of services. Check with your GP as this may change over time.

Peer Support

Spinal Talk www.spinaltalk.com.au (02) 9808 9628

SCIA Peer Support Program www.scia.org.au (02) 9661 8855

Dad Had A Spinal Injury, and What Happened Next
www.aci.health.nsw.gov.au/__data/assets/pdf_file/0010/155287/dad_had_a_sci_Oct2406.pdf

Carers NSW for Carer Support Groups in your local area www.carersnsw.asn.au (02) 9280 4744

Parent Line for advice and information for parents with children up to 18 years.
www.parentline.org.au 1300 130 052

Lifeline: 13 11 14

Child, Adolescent and Family Team – Local Community Health Service
www.chw.edu.au/healthykids/nsw_child_and_adolescent_mental_health_services.pdf

Karitane for 24-hour parenting information and counselling
www.karitane.com.au (02) 9794 2350 or 1800 227 464 outside Sydney

Playgroup NSW:
www.playgroupaustralia.com.au/nsw (02) 9684 5273 or 1800 171 882

Tresillian for 24-hour information and counselling for parents or carers of children under 5 years
www.tresillian.net (02) 9787 0855 or 1800 637 357 outside Sydney

NSW State Spinal Cord Injury Service Directory of Information and Support
www.aci.health.nsw.gov.au/__data/assets/pdf_file/0004/155227/sci_directoryweb.pdf